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"It's tough because I see that it's upsetting her. . .": A qualitative exploration of parents' perceptions of talking with their adolescents about having a visible difference

Deniz Zelihić[a,*], Heidi Williamson[b], Johanna Kling[a], Kristin B. Feragen[a]

[a] Centre for Rare Disorders, Rikshospitalet, Oslo University Hospital, Norway
[b] Centre for Appearance Research, University of the West of England, Bristol, UK

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ABSTRACT

Many adolescents live with a visible difference that affects their lives in profound ways, but studies investigating parents' perceptions of raising appearance issues during conversations with their adolescent are lacking. As part of a larger study exploring the effectiveness of a web-based intervention (YP Face IT), semi-structured interviews were conducted with 18 parents of adolescents with a visible difference. Thematic analysis revealed four overarching themes: *(1) Conversational settings; (2) Understanding adolescents' feelings and thoughts; (3) Providing parental guidance and encouragement;* and *(4) When the dialogue becomes difficult*. Results showed that parents resorted to specific settings when instigating conversations about appearance, such as when their adolescents expressed a need for emotional care, were perceived to be upset, or whilst managing their condition. The choice of setting was also important as some parents generally felt uncomfortable raising appearance issues with their adolescent, for fear of fueling appearance concerns. Results further suggest that open communication can enable parents to stay informed about their adolescent's psychosocial adjustment to a visible difference. These results stress the need to make available support to facilitate open communication about appearance-related topics between parents and adolescents.

1. Introduction

Multiple conditions, injuries and treatment side effects can affect an individual's appearance. For example, some acquire a visible difference as a result of an accidental injury (e.g. burn), a skin condition (e.g. psoriasis), or medical intervention (e.g. chemotherapy). Others are born with a visible difference, including those with a craniofacial condition (e.g. cleft lip and palate) or a missing limb (Rumsey & Hamlet, 2017). Living with a noticeable visible difference that is not "culturally sanctioned" (Kent & Thompson, 2002, p.103), can be particularly challenging for adolescents in societies where appearance is highly valued (Bradbury, 2012; Rumsey & Harcourt, 2012).

The exact number of adolescents living with a visible difference is unknown, however, estimates from the UK suggests that around one in 44 adolescents have a visible difference located on their face or body (Changing Faces, 2010). Research and clinical experience suggests that these adolescents may experience a range of social challenges that can be psychologically demanding, such as teasing and bullying from peers (Van Geel et al., 2014; Feragen & Stock, 2016), being stared at by others (Tiemens et al., 2013), or name-calling and impersonation (Carroll & Shute, 2005). Children and adolescents who are visibly different may also be perceived more negatively by their peers and rated as less attractive (Masnari et al., 2013; Jacobs et al., 2020). Fear of being negatively evaluated by potential romantic partners may also deter adolescents from engaging in romantic relationships, a key developmental task and potential source of self-esteem (Griffiths et al., 2012). Given the many social challenges and potentially stigmatising experiences, it is not surprising that anxiety levels may be more elevated in adolescents with a condition that affects their appearance (van Dalen et al., 2020).

Adolescence is a time when young people usually start to form their own identities (Erikson, 1968). Identity development is typically related to relationships with family members, especially parents (Crocetti et al., 2017). During this stage, developing secure attachments and forming and maintaining stable social relationships with, for example, parents and peers, can also positively impact psychosocial functioning (Bowlby, 1973) and in particular the development of self-esteem (Harris & Orth, 2019). Self-esteem may be especially important during adolescence, because of its

* Corresponding author at: Centre for Rare Disorders, Oslo University Hospital, PB 4950 Nydalen, 0424, Oslo, Norway.
E-mail addresses: deniz.zelihic@outlook.com, denzel@ous-hf.no (D. Zelihić).

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crucial impact on adolescents' lives and well-being, (e.g. through its influence on the quality and size of adolescents' social support networks) (Marshall et al., 2014), and its close relation with, and prediction of, depression and anxiety (Sowislo & Orth, 2013).

Satisfaction with appearance seems to be a key contributor to levels of self-esteem, with previous studies (DuBois et al., 2000; Barker & Bornstein, 2010) suggesting that appearance dissatisfaction predicts lower self-esteem among adolescents. For example, the longitudinal study by Barker and Bornstein (2010) found that 10-year-olds who were less satisfied with their appearance reported declines in self-esteem aged 14. Adolescence is also a time when appearance ideals are especially high and unrealistic (Thompson et al., 2017) and when appearance criticism from peers is ubiquitous. Appearance conversations with peers can influence how individuals view their appearance, with adolescents being particularly susceptible to negative appearance-related comments (Jones et al., 2004).

Given that looking different can constitute an extra psychological burden for some adolescents, receiving relevant support, including emotionally supportive conversations with parents/carers, is therefore important (Keating et al., 2013; Middleton et al., 2018). However, although evidence suggests that family conversations about appearance more generally (e.g. about interchangeable appearance aspects such as clothes and hairstyle) are not typically challenging for adolescents without a congenital or acquired visible difference (Frisén & Holmqvist, 2010), discussing experiences associated with having a visible difference may be more challenging. Adolescents with an "undesirable" aspect to their appearance may avoid drawing attention to, talking about, or disclosing their difference to others for fear of being negatively evaluated or ridiculed (Griffiths et al., 2012), or because others minimise or fail to understand the impact of their visible difference on their lives (Williamson & Rumsey, 2017; Rasmussen et al., 2018). Responsibility to initiate supportive appearance-related conversations is therefore likely to rest with parents/carers. However, as children transition into adolescence and demand greater autonomy and more privacy from their parents (Hawk et al., 2013), communication patterns also shift and adolescents typically disclose less information about their activities and whereabouts (Padilla-Walker et al., 2018). Although parents may have to adjust to changes in communication routines during this developmental phase, promoting a culture of open communication within the family seems to have important implications for adolescents' psychosocial adjustment (Xiao et al., 2011).

Little is known about parents' perceptions of talking with their adolescents about their visible difference, although there is some evidence to suggest that parental support can focus on the facilitation of practical coping strategies, for example by advising on how to answer appearance questions from peers (Klein et al., 2006). In general, previous studies have mainly investigated parents' experiences of having and parenting a child or adolescent with a visible difference (Klein et al., 2010; Nelson et al., 2012; Leemreis et al., 2014; Moss et al., 2020). Results suggest that parents have worries and concerns related to the visibility of their child's or adolescent's condition (Leemreis et al., 2014), and how peers and other peoples' perceptions could affect their adolescent's self-esteem and confidence (Klein et al., 2010). Parents also go through their own phase of emotional experiences related to the social consequences of having a child or adolescent with a visible condition (Nelson et al., 2012). They may find it difficult to raise appearance-related issues, feel insecure about how and when to address such issues, and which words to use (Thornton et al., 2021). Evidence also suggests that health professionals, who may also play significant roles in the lives of adolescents with a visible difference, have similar concerns (Hamlet et al., 2017; Williamson & Rumsey, 2017; Gee et al., 2019). Due to a lack of knowledge about the psychosocial impact of living with a visible difference and fear of causing harm by raising sensitive questions, many lack confidence in engaging adolescents in conversations about their visible difference within clinical settings. The subject is also often avoided, which can constitute a significant barrier to addressing appearance concerns (Hamlet et al., 2017; Williamson & Rumsey, 2017; Gee et al., 2019).

As parents in main care-giving roles are often a significant source of support, it is essential to gain a better understanding of their experiences of raising and discussing appearance issues with their adolescents and factors that facilitate or hinder this dialogue. Knowledge about parental experiences may shed light on unmet support needs and provide guidance to social workers and healthcare professionals on how to support parents who may struggle to discuss appearance with their adolescent, and educate parents about the potential perceived benefits of such conversations.

1.1. Aim

The aim of the current study was to conduct an in-depth exploration of parents' perceptions of talking with their adolescent about appearance and their visible difference. This aim is encapsulated in the following research question: *How do parents experience communicating about appearance issues with adolescents who have a visible difference?*

2. Methods

2.1. Ethical considerations

Ethical approval was given for the study from the Regional Committee for Medical Research Ethics (Health Region South-East, reference number: 2015/2440) and accepted by the Data Protection Office based at Oslo University Hospital. All participants provided a signed consent form before enrolment. In order to preserve anonymity, pseudonyms were given to participants when using direct extracts and quotes. Furthermore, when referring to adolescent characteristics such as age and condition, only broad categories are provided (e.g. craniofacial condition, age 14-16 years).

2.2. Research team

The research team consisted of four members with similar professional backgrounds, three of whom have experience of conducting research in appearance and body image. The first author is a PhD candidate with a master's degree in educational-psychological counselling and one year of professional counselling experience. The first author has experience of publishing qualitative research and underwent qualitative research training as part of a PhD programme in psychology. The second author is a health psychologist with extensive experience of conducting visible difference research with young people and their families. The third author is a licenced clinical psychologist with a PhD in developmental psychology and experience of conducting body image research with adolescents. The last author is also a licenced clinical psychologist and expert in appearance research on congenital craniofacial differences. The first and last authors designed the aim of the present study, in close collaboration with the second author.

2.3. Study design

A critical realist approach based on the philosophy of Bhaskar (1975) underpinned the study design and interpretation of research results. This approach assumes that an external and objective world exists independently from our perceptions (Sayer, 2000, p. 7), yet acknowledges the meaning of individuals' subjective understandings and interpretations (Wynn & Williams, 2012). Importantly,

critical realism asserts that this authentic, but socially influenced, reality can be accessed via research in order to bring about progressive change (Houston, 2001). A critical realist approach is therefore compatible with the aims of this research; to gain a practically useful insight into the personal experiences of parents as well as the social mechanisms that influence their lives and perceptions, with the overall objective of identifying any unmet needs.

Given the limited evidence base, and in line with a critical realist approach, a qualitative exploratory approach using semi-structured interviews was utilised (Green, & Thorogood, 2018). Semi-structured interviews provided a basis for a systematic exploration of topics using pre-set open-ended questions (DiCicco-Bloom & Crabtree, 2006), which remained focused on the key topic whilst allowing for participant-led exploration.

The study was conducted at the Centre for Rare Disorders, Rikshospitalet, Oslo University Hospital, Norway, as part of an ongoing larger mixed methods study and randomised control trial (RCT) in Norway to assess the effectiveness of the Norwegian version of a web-based psychosocial intervention for adolescents with a visible difference aged 12-17, Young Person's Face IT Norway (YP Face IT-N). Adolescents were informed about the YP Face IT-N trial via direct invitations sent from specialised medical treatment teams (e.g. craniofacial) and advertisements in local health care settings and via patient organisations or social media. Those who were interested and eligible for inclusion provided informed consent. As part of the RCT (Trial registration number: NCT03165331) design, participating adolescents and one of their parents were invited for interviews three and six months from baseline to provide qualitative feedback on their experiences of the study.

2.4. Recruitment and participants

The majority of participants in this study were parents of adolescents who were enrolled in the YP Face IT-N RCT between October 2019 and February 2020. During this period n = 15 parents were invited to take part in the current study and all 15 accepted. At the time of the interviews, adolescents had been in the trial for 3 months, nine were in the intervention group and had completed YP Face IT-N, and six were in the control group and had not completed the intervention.

In addition, the research team extended recruitment to parents of adolescents who had declined to participate in the RCT. This decision was prompted by a request from a mother of an adolescent who had received, and declined, a direct invitation to join the RCT. This parent wanted to share her thoughts regarding the impact of this invitation on communication about appearance within her family. The team decided that diversifying the sample, by including parents of adolescents who chose not to engage in the RCT, could potentially add depth to the data and greater understanding of the topic under investigation. The YP Face IT-N trial advisory group, which consists of 15 parents of children and adolescents with visible differences and representing different patient organisations related to diverse conditions leading to a visible difference, therefore agreed to disseminate a further invitation to parents of adolescents not participating in the study. Our intention was to give parents the opportunity to share their experiences of talking about appearance-related topics with their adolescents, whether their adolescent was part of the study or not. Three parents of non-participating adolescents were recruited.

The final sample included 18 parents (three fathers and 15 mothers). Adolescents were eight males and ten females with a range of different appearance-altering conditions, such as missing limbs and craniofacial (e.g. cleft lip and palate) and skin conditions (e.g. ichthyosis). Differences in parental experiences as a result of their adolescent's allocation to either intervention and control groups, or non-participation in the trial, were considered. Notably, to facilitate adolescent engagement with YP Face IT-N, parents of adolescents in the intervention group were provided with a short document including questions they could ask their adolescent after each YP Face IT-N session. As this document did not include content on parental support skills or how to improve parent-adolescent interactions and/or communication, parents of adolescents in both groups were included. Nonetheless, consideration of adolescents' experiences in relation to the YP Face IT-N RCT was considered during the analysis of parent data.

2.5. Data collection

Semi-structured in-depth interviews were conducted via telephone and lasted on average 35 minutes (range: 17-56 minutes). Telephone interviews were chosen in order to increase geographical reach. Most interviews were performed by the first author ($n = 11$), two by a research assistant, and five by the last author.

A semi-structured interview guide was used. Parents of adolescents in the intervention group were asked additional questions concerning the intervention. The interview guide was originally developed by Dr. Heidi Williamson, who also developed the original English version of YP Face IT (Williamson et al., 2016). The interview guide was translated into Norwegian by the first author. Questions explored parents' perceptions of their adolescents' experiences with having a visible difference, including questions such as: "What do you think your son/daughter thinks about his/her appearance?", "Have you experienced that appearance is a problem for your son/daughter?", "Do you think that your adolescent's appearance has influenced his/her social experiences?" and "Do you know whether he/she has experienced any challenging situations related to his/her visible difference for the last three months that were difficult to manage?".

For the purpose of the present study, two open questions were added in the Norwegian version before initiating data collection, to more specifically explore parents' perceptions of appearance-related conversations: "How do you, as a father/mother, feel about talking about appearance with your son/daughter?" and "What do you believe your son/daughter feels when talking about appearance with you as a parent?"

Questions were followed-up by a range of probes, with the purpose of gathering more information about how parents perceived appearance conversations to unfold, how they believed such conversations affected the adolescent, and potential barriers or facilitators hindering the appearance dialogue. Examples of follow-up questions were: "How often do you have conversations with your son/daughter about his/her appearance?", "What do you think is the reason for not talking about appearance-related topics with your son/daughter?" and "Do you have any examples of appearance-related situations that you could talk with your son/daughter about?". No changes were made to the interview guide as data collection progressed.

2.6. Data analysis

An inductive, data driven approach to thematic analysis was chosen based on the six phases outlined by Braun & Clarke (2006), and themes were constructed through identified patterns in the data. The first phase in the analytic procedure involved transcribing the interviews verbatim (15 interviews were transcribed by the first author and three by a research assistant). All transcriptions were read several times and data was extracted from the full interviews. The first and last author highlighted excerpts containing information about conversations or lack of conversations between parents and adolescents. Excerpts about parents' perceptions regarding their child's experience of living with a visible difference or experiences with participating in the YP Face IT-N RCT were excluded,

Table 1
Overview of overarching themes, subthemes, example codes and number of parents represented in the subgroups (i.e. intervention, control or non-participating).

Overarching theme	Subtheme	Example codes	Subgroups: Intervention, Control, Non-participating
Theme 1: Conversational settings	Finding the right occasions to raise appearance issues	Safe context (need for care)	9/9; 5/6; 1/3
	Young Person's Face IT: enabling conversations	Basis for conversation (YP Face IT)	5/9; 2/6; 1/3
Theme 2: Understanding adolescents' feelings and thoughts	Being different	Feeling different, otherness	8/9; 6/6; 3/3
	Treatment-related talks	A wish for corrective surgery	5/9; 1/6; 2/3
	Dealing with difficult situations	Unwanted comments at school	2/9; 4/6; 1/3
Theme 3: Providing parental guidance and encouragement		Encouragement and support	5/9; 2/6; 2/3
		Creating a sense of accomplishment	
Theme 4: When the dialogue becomes difficult	Parents' feelings when engaging in appearance talk	Tough when appearance becomes a subject	9/9; 6/6; 3/3
	Reflecting on conversational boundaries	Adolescent's openness to talk	8/9; 3/6; 3/3

unless they contained relevant information about potential conversations. The first author then coded the data on a semantic level (i.e. writing descriptive words or phrases adjacent to associated excerpts from the transcripts). The first five interviews were coded in tandem with the last author. Disagreements during the analysis process were discussed and resolved between the first and last author. Specifically, this was done by systematically going through all coding for the first five interviews until agreement on the level of coding was reached. This process ensured consistent coding. After the material had been coded, the first author categorised codes into broader units on a latent level (i.e. interpreting emerging patterns and categories). Thematically related codes were grouped into categories and were identified as candidate subthemes. Subthemes were checked for thematic similarities and grouped into overarching themes. Codes, subthemes, and overarching themes were generated iteratively and continuously compared back to the initial codes and excerpts. This analysis generated four overarching themes and seven subthemes that were clearly defined and named (see Table 1). Finally, the analysis was formed into a coherent story with distinct names for overarching themes and subthemes, supported by evidence from data extracts. Overarching themes and associated subthemes are illustrated with excerpts from the transcripts. In order to increase transparency, the number of parents describing a particular phenomenon is provided in the results section, with the purpose of precisely characterising the diversity of perceptions among parents and the amount of evidence that supports a particular theme (Maxwell, 2010).

After initial theme construction, all transcripts were re-read with the intention of searching for potentially new information related to parents' experiences of communicating about appearance issues with their adolescents that could inform the themes. No new information was discovered and, considering the review of all transcripts and the study's exploration of a relatively unexplored area, it was determined that the 18 parents provided enough information about the topic under investigation.

To enhance the trustworthiness of the study (Tracy, 2010), a summary of the study findings was sent to the YP Face IT-N RCT advisory group, for their review and to check that the analysis resonated with their members' experiences. The advisory group provided feedback that was accordant with the themes identified.

3. Results

Four overarching themes and seven subthemes were constructed from the inductive thematic analysis (see Table 1).

The themes describe how and under what circumstances parents engage in conversations with their adolescent about different topics related to appearance and experiences in daily life. The themes also illustrate how parents experience this communication. Table 1 includes the proportion of parents from each of the three subgroups (who had adolescents in the intervention group, control group, or non-participating adolescents).

All parents were asked how often appearance-related conversations were taking place with their adolescent. Eight of the 18 parents reported that conversations happened frequently, often when the adolescent experienced a difficult situation. Eight of the 18 parents described having less frequent conversations, also often prompted by the adolescent's experiences, whereas two parents described not talking about appearance-related topics with their adolescent at all.

3.1. Conversational settings

This theme captures the parents' experiences of the different settings and circumstances in which conversations about appearance-related topics occurred with their adolescents. This theme was present in all three subgroups.

3.1.1. Finding the right occasions to raise appearance issues

Ten of the 18 parents explicitly described settings in which conversations occurred. Although parents acknowledged the ideal setting to raise appearance issues did not exist, having enough time and being in the right context, such as when relaxing on the couch in the evening, was deemed important: "...you kind of have to have a nice setting...it opens up the possibility to bring up such [appearance-related] themes" (Lisa, son, 12-14 years, skin condition). Other appropriate settings could arise if the adolescents expressed a need for emotional care, when managing or discussing the adolescents' condition, or when discussing future treatment options.

Of the parents who mentioned the conversational settings they used when raising appearance issues, three parents (all from the intervention group) expressed that conversations occurred "naturally", when and if a topic arose that could be discussed further. These parents had the impression that it was important for them not to raise the topic of appearance "out of the blue". They elaborated this as a need to feel "right" about raising the issue, because they were aware that talking about appearance could potentially affect their adolescent's current mood by evoking negative thoughts and feelings. For example, one of the fathers described how he might tentatively attempt to engage in appearance talk if he noticed that his daughter's condition caused physical discomfort:

> When we see that she struggles, '[then we ask] are you in [physical] pain?', [that's when] it becomes a topic and then we just try

in a humble way to start a dialogue and see whether she is interested in talking about it. So, we don't force [the conversation]. . . (Ethan, daughter, 12-14 years, bone condition)

When discussing who initiates appearance conversations, parents had different experiences. Some had adolescents who instigated conversations, whereas other parents felt they had to raise the subject themselves:

. . .She [the adolescent] only answers my questions and says that everything is ok, and maybe she doesn't have any need to talk about it with us. . .I have thought for myself that if she did have a need [to talk] she would have initiated conversations herself. . . (Emma, daughter, 15-17 years, skin condition)

Other opportunities to talk about appearance were also described. In all three subgroups (12 of 18 parents in total), there were descriptions of how the parents monitored their adolescent's behaviours or feelings, looking for evidence of distress, and carefully judging when to intervene and initiate appearance conversations. For instance, Christina (daughter, 14-16 years, craniofacial condition) said: ". . .if she is a little bit angry (. . .) if I observe it early enough, then I can go up and talk to her. . ." Thus, the adolescent's body language, behaviours, and emotional state were described as important signals for the parents in terms of reaching out and approaching them for a conversation.

3.1.2. Young Person's Face IT: enabling conversations

Eight of the 18 parents reported that their adolescent's experience of the YP Face IT-N project created a starting point for conversations about appearance. One of the mothers of an adolescent from the intervention group expressed how her daughter's interest in talking about her appearance increased with participation in the project: ". . . [The adolescent benefited from] being heard and actually have an interest in talking about it. Because usually, we don't talk that much with [her] about this" (Natalie, daughter, 14-16 years, craniofacial condition). Another mother described that her daughter had mentioned that completing YP Face IT had helped her become more analytical about her own reactions and strategies in past situations: ". . .she has seen for herself that 'I reacted in this way there'. . .a little bit like that, her experiences, she has understood herself and situations a bit more. She has specifically talked to me about this. . ." (Meryl, daughter, 13-15 years, craniofacial condition). Completing YP Face IT also generated conversations about the adolescents' own experiences:

He was working with the project [YP Face IT] yesterday, started with it, and then he said 'Mom, come and look', and then he said that some people say they think adults shouldn't stare, that they should know better. I replied 'Yeah, don't you feel the same way?', 'No, people should be allowed to stare if they want to, I too can stare sometimes'. (Cecilia, son, 12-14 years, craniofacial condition)

In contrast, one mother described how her daughter reacted negatively after receiving an invitation letter to participate in the YP Face IT-N project: ". . .it was impossible for me to talk sensibly with her afterwards [after opening the invitation letter] about participation in the study, or discussing getting some help around this. . .because this [appearance] is so vulnerable for her, it just became so difficult" (Sophie, daughter, 13-14 years, craniofacial condition).

3.2. Understanding adolescents' feelings and thoughts

This theme illustrates parents' experiences of how conversations enabled them to better comprehend their adolescent's feelings, thoughts, and adjustment to having a visible difference. Parents from all three subgroups were similarly represented in this theme and its subthemes.

3.2.1. Being different

Sixteen of the 18 parents described that their adolescents often expressed feelings about having a visible difference during conversations. This is exemplified by a mother who recounted a conversation where her son shared his thoughts about his appearance: ". . .when I have asked him earlier, he tells me that he is ashamed of his [body part]" (Lisa, son, 12-14 years, skin condition). One topic that was particularly present and described by eight of the 18 parents was their adolescent's disclosure of feeling different: ". . .she doesn't want to be any different than others" (Jane, daughter, 12-14 years, craniofacial condition). One of the mothers described how conversations had revealed a developmental change in her daughter's feelings about being visibly different. When younger, her daughter shared how proud and special she felt because of her difference. When older and in response to negative reactions from other children to her difference, she shared her shift in perspective with her mother:

. . .she came home one day and said, 'You know what mom? When the other kids ask me if they can see [body part] (. . .), I don't want to [show them] anymore, because now they just tell me 'ugh". So, from then on it was that thing about being different (. . .) So from that time, she began to hide that she was [different and] had a prosthesis. (Linda, daughter, 12-14 years, skin condition)

3.2.2. Treatment-related talks

Eight of the 18 parents recounted conversations with their adolescents about treatment-related issues, such as reconstructive surgery or other surgical interventions, which in turn gave parents a clearer picture of how their adolescent felt about their appearance and/or condition, and future treatment: ". . .she is going to ask for a [surgical] correction on her [body part]. She has said that she looks forward to getting it done" (Natalie, daughter, 14-16 years, craniofacial condition). Another mother described how conversations could also provide an opportunity to discuss treatment options, and potentially help the adolescent reflect upon such issues:

. . .when she asked whether it was possible to 3D-print an [body part], then we could talk about the possibility that this would turn out to be fine and very good in the future, one cannot know now, because new research is [bringing improvements] all the time. We can talk about it like that. . . (Jane, daughter, 12-14 years, craniofacial condition)

Hence, the parents described that treatment-related conversations helped them to better understand their adolescent's emotional response to aspects of their visible condition.

3.2.3. Dealing with difficult situations

Seven of the 18 parents provided detailed accounts of their adolescents recalling challenging social experiences at school or during social interactions with peers. Parents described these experiences as emotionally taxing for the adolescent which triggered disclosure about the course of the event:

Yeah, she [the adolescent] talked about [the experience] at home. She told about it immediately when she came home, because it affected her. Yeah, so she is very open with us at home around such things. It is at least how we [parents] experience her. . .she can tell about such things without me needing to ask, 'What happened today?'. . . (Meryl, daughter, 13-15 years, craniofacial condition)

One of the fathers recounted a dialogue with his daughter who was worried that her appearance affected one of her friendships. In this particular conversation, the father gained insight into how appearance concerns influenced his daughter's interpretation of her relationship with her friend:

> . . .But as I try to explain to her, it is just the way it is with these friend-groups, they [adolescents] switch back and forth between friends all the time. It can be times where she has been a lot with one [of her friends] and then suddenly she wants to be with someone else, and then after some time they're back together, right. So, it has nothing to do with her facial appearance, but clearly, she draws those conclusions, right, because she often has low self-confidence because of [her appearance]. (Ethan, daughter, 12-14 years, bone condition)

3.3. Providing parental guidance and encouragement

The third theme reveals parents' experiences of how talking openly about different appearance issues enabled them to encourage, positively reinforce, and guide their adolescents, helping them to adjust to their visible difference and cope with difficult situations. When talking about these experiences parents perceived openness to be a crucial strategy that contributed to their adolescent's positive psychosocial adjustment. This theme was present in all three subgroups.

Nine parents expressed that conversations became a tool used to provide support for their adolescents. These parents seemed to shift the topic of conversation consciously to a more positive focus, as exemplified by one of the mothers: ". . .we have kind of focused on positive aspects and talked a lot about the fact that everyone has something [that is different]" (Jane, daughter, 12-14 years, craniofacial condition). Engaging in dialogue provided the ideal occasion for one of the fathers to encourage his daughter whenever she was feeling disheartened. This father emphasised the need for him to be more attentive to his child's support needs, because of the additional challenges associated with feeling different to peers:

> . . .So that's how we're continuously working with her and encourage her and support her with all our strength in order for her to feel a desire and have a will to do things, because it is so easy to get in that [state], in that "basement" where everything is dark and sad and 'I hate everybody' and 'I hate myself' and 'I look ugly' and 'No one wants to be with me'. . .So we [parents], we lift her up. She can fall down into that "basement" sometimes, but we lift her up. (Ethan, daughter, 12-14 years, bone condition)

Another mother highlighted how talking openly with her daughter gave her the opportunity to provide guidance on the importance of being open with her friends about situations she felt were difficult. After considering her mother's guidance, the mother described her daughter's sense of accomplishment: ". . .she experienced appreciation [from her friends]. She felt that it helped her a lot, [being open] was something that provided a little relief. . ." (Sophie, daughter, 13-14 years, craniofacial condition). As such, the parents felt that conversations enabled them to provide personalised guidance and support to their adolescents.

3.4. When the dialogue becomes difficult

The fourth and last theme encapsulates the parents' experiences of and reflections on managing the more challenging aspects related to talking to their adolescent about their appearance and condition, and the impact of these conversations on the parents. This theme, in which parents from all subgroups were equally represented, explores parents' reflections on how adolescents perceive talking about appearance issues.

3.4.1. Parent's feelings when engaging in appearance talk

Sixteen parents talked about how they felt when having appearance conversations with their adolescents. Eight of these parents found it challenging to raise appearance issues, because they observed that it was a burdensome topic for their adolescent. One of the mothers expressed this in specific words: ". . .it's tough because I see that it's upsetting her. . ." (Meryl, daughter, 13-15 years, craniofacial condition). The two parents that described not talking about appearance with their adolescent (one from the intervention group and one from the non-participating group), found the lack of conversations to be emotionally difficult for themselves and wished for appearance conversations: "I feel that it's sad that she really doesn't want to talk about it" (Eliza, daughter, 12-14 years, craniofacial condition).

Conversely, for eight of the parents (i.e. from the intervention and control group), raising appearance issues was not perceived as an intrinsically difficult task because of the good and open relationship they experienced with their adolescent. One mother clearly expressed how the positive relationship she shared with her adolescent underpinned their ability to discuss appearance issues openly: "I experience it [talking about appearance] to be rather easy (. . .) in fact, we are quite open around different topics, so maybe it is the fact that we have a good relationship with him that makes it easy" (Kate, son, 15-17 years, congenital limb condition).

3.4.2. Reflecting on conversational boundaries

Two mothers, one from the intervention group and one from the non-participating group, described that it was difficult to talk openly about appearance issues, due to a perceived lack of interest or motivation from the adolescent. One of the mothers recalled a situation when she was surprised to overhear her son talking about his appearance and condition with friends, because he had previously shown no interest in discussing these topics with her. As a result, she had the perception that she was not invited into her son's "conversational zone". Similarly, another mother shared this experience when trying to talk with her daughter about her appearance:

> I try to bring it up and I try to talk it up, right (. . .) but it's like she won't comment on anything and doesn't say anything, usually she prefers not to respond to my questions. I think it is obvious that [appearance] is sensitive. (Eliza, daughter, 12-14 years, craniofacial condition)

Because talking about appearance was experienced as a sensitive endeavour and described in all subgroups (by 11 parents), parents expressed the need to be attentive and considerate about the adolescent's motivation to engage in a dialogue: ". . .I think that there is a clear boundary on how much I should ask and when it turns out to be pestering, like if I ask the same things many times, it can be perceived as nagging" (Emma, daughter, 15-17 years, skin condition).

One of the mothers (from the intervention group) also described that she was very conscious about the way she talked with her son and reflected upon the importance of being cautious about not using words that could potentially cause appearance concerns.

Although 11 parents from all three subgroups perceived that their adolescent did not find it challenging to talk about their visible difference, attempting to engage in appearance talk could still be difficult. For instance, one of the mothers felt that when approaching her son to talk about appearance issues, it was not unlikely that he would feel that she was: ". . .making a deal out of something he initially didn't think was a problem" (Kate, son, 15-17 years, congenital limb condition). Similarly, another mother had

the impression that her son carried more thoughts than he was able to share with her, because she perceived that he felt that: "... [appearance] was not really something to talk about" (Julia, son, 14-16 years, skin condition).

4. Discussion

The current study examined parents' perceptions of talking with their adolescent about topics related to appearance and their visible condition. Very few studies have investigated how parents experience talking with their child or adolescent about their visible difference, and the challenges and benefits of having such conversations. Therefore, this study provides a unique contribution by highlighting the different settings and contexts that facilitate appearance conversations, how conversations enable parents to elicit information about their adolescent's psychosocial adjustment to a visible difference and provide support through advice and guidance, and presents barriers that may hinder constructive appearance conversations. Overall, parents from all three subgroups were similarly represented across most themes. Still, a somewhat higher proportion of parents from the intervention group talked about the need to find the right context for appearance conversations, providing guidance and encouragement, and reflecting on conversational barriers.

Irrespective of whether or not their adolescent had experience of completing YP Face IT, findings revealed that some parents took care to ensure that they mitigated the risk of exacerbating distress when taking the decision to instigate conversations about appearance. They considered the timing and setting of the event, such as when their adolescent expressed a need for care, when helping their child to manage their condition, and when observing behaviours that indicated the adolescent was struggling. Similar findings were reported in a study by Middleton et al. (2018), where parents of children with sickle cell disease were alert to their child's physical and emotional well-being in order to initiate conversations.

The finding that parents in the current study were cautious or hesitant about initiating conversations reflects their apprehension about randomly raising a potentially sensitive topic that may not be perceived as welcome or helpful by their adolescent. Previous studies have also illustrated that parents use of language when describing their adolescent's appearance or condition may cause emotional distress (Puhl & Himmelstein, 2018) and that conversations may be perceived by the adolescent as a reminder of his or her difference (O'Toole et al., 2016a). Indeed, evidence of adolescents ignoring or responding negatively to such approaches was reported by parents in this study and suggests parental concern is well-founded, but ultimately may impede initiatives to instigate conversations that could ameliorate adolescent concerns.

To encourage supportive dialogue, parents may therefore need to identify and exploit contexts and settings that facilitate appearance conversations. For example, current findings showed that the YP Face IT-N RCT provided a conversational setting for parents in all three subgroups. Although tentatively, this result indicates that adolescents' affiliation with an appearance-specific RCT, regardless of the degree of participation, can facilitate a dialogue about appearance among some parent-adolescent dyads. This is also consistent with results from another study, the Dove Self-Esteem Project, where participation led to increased conversations about body image between mothers and daughters (Diedrichs et al., 2016). Intervention studies may therefore have the potential to facilitate conversations between parents and adolescents about sensitive topics such as appearance.

In three subthemes, descriptions from parents in the intervention group were proportionally more frequent than descriptions from the control- and the non-participating group. This could indicate that positive conversational experiences may have been influenced by the intervention content. YP Face IT teaches and encourages adolescents to practice coping strategies in order to manage staring, bullying, and anxiety, and changing negative thoughts about their own appearance (Williamson et al., 2016). Although parents do not have access to YP Face IT, and the intervention does not include information about how to improve interaction and communication skills between parents and adolescents, it does provide parental guidelines that encourage parents to discuss intervention content with their adolescent. The intervention may have therefore, indirectly, facilitated conversations about appearance. Relatedly, it could also be the case that the interviews conducted with the parents and/or adolescents impacted their experience of participating in the YP Face IT-N RCT. Nonetheless although completion of the intervention might have helped some adolescents or parents to take the initiative for a conversation, the results still indicate that parents from all subgroups had relatively similar experiences.

Interestingly, almost half of the parents in the current study, and all parents from the control group, expressed that they were confident to discuss and address appearance issues, because they experienced a good and open relationship with their adolescent. Similar results were found in previous studies (Frisén & Holmqvist, 2010; Wilson et al., 2010), with community samples of adolescents. For instance, the study by Frisén and Holmqvist (2010) showed that, during appearance conversations with their parents, adolescents often felt that their parents viewed their appearance positively. However, conversations were typically related to clothes and hairstyle, rather than aspects concerning the physical body. Moreover, the study by Wilson et al. (2010) indicated that developing a good relationship was important for parents and their adolescents when facilitating conversations about sex-related topics, another potentially sensitive conversational topic. When combined, these results suggest that the relationship parents have with their adolescents may be a vital component when instigating difficult conversations and may constitute a prerequisite in parents' initiative to talk about sensitive issues.

The current study demonstrates that talking openly about appearance issues may benefit both parents and their adolescents. Parents in this study expressed that having conversations enabled them to explore the adolescent's thoughts and feelings related to having a visible condition and coping mechanisms used in difficult situations, which in turn strengthened the parents' ability to support their adolescents in suitable ways. Conversations also provided opportunities for parents to acknowledge their adolescent's difficult feelings, and provide encouragement, guidance, and advice. For example, one of the mothers encouraged her daughter to talk openly with her friends about difficult experiences related to her visible difference. As a result, her daughter felt that being open with her friends provided emotional relief. Other studies looking into parents', children's, or adolescents' experiences with talking about sensitive issues, have revealed several benefits of open communication, such as improved management and adjustment to having a congenital condition (DeBoer et al., 2017; Middleton et al., 2018; O'Toole et al., 2019), and more confidence in peer interactions (O'Toole et al., 2019). Additionally, talking openly allows parents to educate their adolescent on how their congenital condition makes them different from peers (Middleton et al., 2018), which may increase the adolescents' awareness about their own situation. Pariera and Brody (2018) also found that older adolescents perceived openness and honesty to be their parents' strengths when talking about sex-related topics. Open and honest communication is therefore not only highlighted as a strength in parents' conversational approach, but may also be favoured by adolescents when discussing a sensitive topic. This assumption is supported by a study that found better psychosocial adjustment in adoles-

cents who perceived higher levels of open communication with their parents (Xiao et al., 2011).

However, having open conversations about sensitive issues is not without its challenges. Present findings reveal barriers that parents faced when trying to initiate appearance-related conversations. Some parents perceived that adolescents were not always open to talk about their thoughts, feelings, and social encounters, and avoided responding to questions about appearance. Resorting to avoidance when faced with difficult questions is not uncommon among adolescents and may reflect a desire to regulate personal boundaries (Golish & Caughlin, 2002). For instance, adolescents may feel that parents become overprotective or have unnecessary concerns when confronted with questions (e.g. about their condition or appearance) that they themselves do not necessarily perceive as problematic (O'Toole et al., 2016a). At worst, frequent questioning may be perceived by adolescents as obtrusive and an invasion of privacy, which may in turn impede future conversations and restrict parents' future knowledge about their adolescent's experiences (Hawk et al., 2013). This does not mean that parents should be afraid of asking questions and engaging in conversations. However, parents should attempt to be attentive to how their language and overall communication is perceived by the adolescent. For instance, a recent study by Lydecker et al. (2018) found that parents' fat talk (e.g. negative comments about weight and body image) directed towards their child negatively influenced the child's eating behaviours and weight. Similarly, another study showed that increased levels of fat talk and old talk (e.g. age-related appearance concerns) between mothers and daughters were indicative of higher levels of body dissatisfaction (Arroyo & Andersen, 2016). Hence, studies demonstrate the unfortunate consequences that parents' language use may have on adolescents' own appearance perceptions and stresses the importance for parents to be considerate when raising sensitive issues. Almost half of the parents in the current study, most of them from the intervention group, also described that their adolescent felt different as a result of their visible difference. One of the mothers, in particular, described how her daughter became less open to reveal her visible difference to others as she became older, because of stigmatising responses from peers. Thus, in addition to the importance of being attentive to how they communicate with their adolescents about appearance issues, parents may also have to consider how to navigate conversations as their adolescent's transition from childhood to adolescence and become more aware of and worried about how they differ from peers (Ballard et al., 2019).

In the current study, across all subgroups, talking about the adolescent's visible difference was also emotionally difficult for some of the parents. These parents found it challenging when adolescents did not want to engage in appearance conversations. Studies point to several barriers that parents face when raising sensitive topics with their adolescents, including concerns about causing worries when discussing the condition (O'Toole et al., 2016b), feeling uncomfortable and lacking knowledge or communication skills about the topic for discussion (Wilson et al., 2010), and lack of confidence to instigate conversations (Morawska et al., 2015). These barriers may potentially act as stressors for parents and impede constructive conversations with their adolescent. However, although talking about sensitive issues can be uncomfortable for parents and adolescents, these difficult conversations often provide emotional relief for adolescents, enable support from family members, and can improve parent-adolescent relations (Keating et al., 2013).

4.1. Parents' perceptions in light of a critical realist perspective

From a critical realist viewpoint, it could be argued that different settings, openness to talk, and the relationship between parents and their adolescents, constitute important mechanisms that enable conversations about appearance. Although parents perceived conversations as an approach to explore their adolescent's thoughts and feelings, their knowledge of adolescents' inner experiences will remain limited. Correspondingly, exploring parents' experiences of addressing appearance issues with their adolescents through qualitative interviews may provide an in-depth, albeit limited, understanding of the parental perceptions.

4.2. Limitations

Although the current study provides unique insight into parents' experiences of appearance conversations with their adolescent, some limitations require consideration when interpreting the results. First, interviews were conducted by telephone, which may hinder the interviewer's potential to respond to visual cues (Holt, 2010). Video calling was not used due to regulations of ethics for data collection placed by the Oslo University Hospital. Additionally, because thematic analysis (Braun & Clarke, 2006) did not necessitate gathering of visual cues, data collection via telephone calls was deemed appropriate. Although video calls or face-to-face interviews would have provided visual cues, participants can prefer the greater sense of anonymity afforded by telephone calls, particularly when discussing sensitive issues (Fenig et al., 1993). Telephone interviews also facilitated participation for those who were geographically hard-to-reach (Drabble et al., 2016).

Second, although most interviews (73%) were performed by the first author, two other interviewers also collected data. While multiple interviewers can increase the efficiency of data collection, multiple interviewers bring their own experience, expertise and style into the interview setting. Interviewers' knowledge in a certain field or interviewing skills may for example determine the amount of relevant follow-up questions that are asked, which may in turn affect the quality and depth of the data. Interviewers may also differ in how comfortable and confident they feel exploring sensitive questions (Rosenblatt, 2012), or leading participants through the interview guide.

Third, the study sample consisted mainly of mothers and no systematic efforts were made to recruit more fathers. We interviewed the parent who had contacted the research team when enrolling the adolescent into the study. It is well known from the research literature that men are underrepresented in qualitative health research (Polit & Beck, 2008). This is unfortunate because fathers may provide different perspectives of a certain phenomenon and may have other experiences to share. However, although gender differences were not explored, results did not indicate any differences between fathers and mothers in their approach to conversations about appearance. Still, future research on the present topic should aim to include a representative sample of fathers and investigate this issue more explicitly.

Fourth, the majority of the study sample were parents of adolescents that had participated in a larger RCT study evaluating a psychosocial intervention aimed at reducing appearance-related distress. Regardless of which group adolescents were allocated to in the larger study (i.e. intervention, control or non-participating group), the study may have influenced parents' experiences and perceptions in relation to the topic explored. Since 15 of the 18 families had decided to participate in an appearance-related intervention study, it could be that this group of parents were more receptive and less anxious about discussing topics related to a different appearance than parents in general. To address this potential limitation we also invited parents of non-participating adolescents. Interestingly, although only three parents were recruited, their experiences did not seem to differ significantly from the other parents, which may indicate that the present sample still represents parents of adolescents in general.

Fifth, inter-coder reliability (ICR) was not calculated during the analytic phase. While including metrics of ICR may increase the transparency surrounding the coding process (O'Connor & Joffe, 2020), this method is widely debated among qualitative scholars (Yardley, 2000; Braun & Clarke, 2013; O'Connor & Joffe, 2020). For example, a high ICR may not guarantee that a study is rigorous and trustworthy (O'Connor & Joffe, 2020), as this number may only represent how much researchers agree on a set of codes (Yardley, 2000). To maximise the trustworthiness of findings, quality criteria used to guide qualitative research were employed. These included transparent reporting of all analytical steps in the construction of themes and subthemes, analysis validation checks by the RCT trial advisory group (parents of children and adolescents with diverse conditions leading to a visible difference), independent review of the first author's codes and themes by the last author. In addition, the extent of participant support for each theme and subtheme was quantified in the result section (see Table 1).

4.3. Clinical relevance and future research

The results of this study could inform the practice of healthcare professionals and social workers wishing to help parents address sensitive topics with their adolescent and, given some parents' inherent fear of making things worse, give them more confidence to highlight the potential benefits of talking about sensitive issues. For example, parents may be informed that, although some topics are difficult to talk about, conversations may ultimately enable them to provide emotional relief, guidance, and encouragement to their adolescents. Future studies should aim to investigate how adolescents' age, type of condition, and gender may relate to experiences of appearance conversations and consider the impact of developmental changes in communication patterns, for instance from childhood into adolescence. It would also be interesting to explore if parents' gender and body image perceptions influence appearance conversations with adolescents. Future studies should also seek to explore how adolescents themselves experience discussing their visible difference with their parents, and how they benefit from talking about appearance issues. Lastly, in our study, being interviewed about appearance-related concerns may have made parents more attentive to these kinds of concerns in their adolescents, and in turn made them more eager to support their adolescents in completing YP Face IT. Further investigation is therefore warranted on how participation in an appearance-specific intervention might influence interviews conducted in parallel, as well as on how the knowledge gained from interviewing parents and/or adolescents that are actively part of intervention studies may feed back into the intervention and its commencement.

5. Conclusion

The current study explored parents' experiences of talking with their adolescents about their visible difference, which is a rarely investigated subject within visible difference research. Findings indicate that parents carefully consider timing and context before broaching the topic of appearance with their adolescent and can limit conversations to specific settings, for example when perceiving a need for emotional care after a difficult social experience. Appearance conversations can help parents to learn more about their adolescent's adjustment to living with a visible difference, and how they cope with difficult situations. Findings also draw attention to the benefits of communicating openly about appearance issues; parents reported that open and constructive conversations enabled them to provide their adolescents with encouragement, emotional relief, and guidance, which in turn helped their adolescents to reflect upon their situation and strengthen coping skills. However, talking about appearance issues was also reported to be an emotionally taxing endeavour, for parents as well as for their adolescents. This suggests a need to focus on developing interventions that may support both parents and adolescents in talking more openly about sensitive appearance issues.

Author statements

Deniz Zelihić: Conceptualisation, Methodology, Validation, Formal analysis, Investigation, Data Curation, Writing – Original Draft,
Dr. Heidi Williamson: Conceptualisation, Writing – Review & Editing, Supervision
Dr. Johanna Kling: Writing – Review & Editing, Supervision
Dr. Kristin Billaud Feragen: Conceptualisation, Methodology, Formal analysis, Investigation, Writing – Review & Editing, Supervision, Project administration, Funding

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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